

**Family Support Council - Supported Decision Making Session #2:  
Next Steps - Building Ideas and Content for Trainings for DDS And DC Agencies**

*Thursday, March 28, 2019, 12:30-2:30pm at Department on Disability Services,  
250 E Street, SW, Bobby Coward Room Washington, DC 20024*

Purpose: This is the second of two sessions that the Family Support Council is convening for all stakeholders to get broad input into opportunities and perceived barriers to Supported Decision Making in DC, so that everyone: youth, adults, elders with disabilities, family members, service providers and agency staff will play a significant role in designing trainings and SDM rollout at key agencies in DC.

## **EXECUTIVE SUMMARY of Group Discussions**

### **Round 1 – Questions:**

**1) How often should an SDM agreement need to be signed, reviewed, or reassessed?  
How should that work?**

- Whenever a person is dissatisfied, though people should have access to a mediator too. Not all supporters are going to be “yes” people, so agreements should not automatically be eliminated just because there is a disagreement.
- Whenever circumstances change
- SDMA's are a legal agreement, and should be signed, witnessed, notarized, etc.
- SDM agreements should include protocols about when it will be reviewed and how it will be reviewed
- Ask, why do you want to change your supporter?
- How is this person supporting you?
- How does your family communicate/get along?
- When the individual changes their mind and feels that it needs to be changed
- Changed yearly with options to review with life events
- Important to know what the person wants
- The person needs a greater understanding so they can decide how often they want to review
- If someone in DDA supports, maybe there is a question asked annually at an ISP meeting if the person wants to review the SDM
- It should always be emphasized that a person can make a new one when they want – but there should be clear understanding that it is a legal document and it should be a thoughtful process
- SDM agreements should not just be a piece of paper to sign at an ISP meeting and should not have an automatic expiration date. ISP meetings are a place where discussions about SDMA can occur – but don't need to be.
- If the SDMA includes an expiration or review date in the original language

**2) How would we incorporate the use of a “team” of people as supporters (i.e., a group of siblings)?**

- Supporters should not be paid
- How can case managers raise red flags? Who has oversight over supporters? Would that oversight person be on the team of supporters?

- Could supporters choose areas of expertise? Financial? Medical? Living arrangements? Legal? Travel? Dealing with family? Educational? This should be allowed. Everyone should sign the agreement and some will have to commit to more frequent support than others.
- For safety, have backup supporters, or others who know what's going on.
- Relationships mapping and identifying a team (maybe during ISP)
- Use communication styles with different teams
- Consider supporters outside of direct family - parents don't necessarily need to be part of the team
- What are the roles of the team if this is used?
- Perhaps a team based on topic or issue (i.e., one for medical, one for housing)
- Consider location (local or out of state)
- Each person should be able to decide how many supporters they want
- There has to be one agreement for each supporter – so if the person with a disability chooses a team approach – there still has to be an SDMA for each person involved.

**3) How do we make sure all agencies and public service organizations understand SDM? How do we ensure community understands SDM? i.e., banks, medical community, companies**

- For businesses – we should approach the Better Business Bureau, Chamber of Commerce, etc. and inform/educate them
- Public Awareness Campaign – PBS stations, PSA's,
- Peer to peer communication within different communities – doctors, bankers, translate materials into different languages
- Professional conventions, associations – connect with them to see how we can make this make sense to them – table at events?
- Approach religious organizations, disability ministries to educate about SDM
- Incorporate SDM into person centered thinking – talk about these as complimentary practices – “realize you're working for the person”
- Model the Person Centered Training program
- Training should involve people with disabilities and community involvement
- Survey banks, agencies, etc. to promote training
- Webinar series of trainings
- Public campaign to train staff at agencies to medical community to services and companies
- Share with all DC Communities of Practice (i.e., COP-Secondary Transition, Supporting Families, Cultural Competency, School Based Mental Health, etc.)

**Comments/Clarifications Regarding the SDM Law on the Discussion Points/Questions #1-3:**

- SDM is a legal agreement, so if a person is dissatisfied, the form should not be automatically pulled out and re-filled out – a person should be referred to an advocate or attorney

- It should be made clear that the SDM form is not a mandatory form to be filled out every ISP – it should not be the responsibility of the Service Coordinator
- An SDM agreement is powerful in the hands of the person that it's about – that person takes charge of getting it completed and decides how it's used
- There needs to be a separate SDM agreement with each supporter: There has to be one agreement for each supporter – so if the person with a disability chooses a team approach – there still has to be an SDMA for each person involved.
- A the person with a disability may have an SDMA and power of attorney (it is not either/or)
- Comments on mediation: changes to a SDMA happen when the person with a disability wants it, a designated supporter wants a change, and if there was any expiration date on the original SDMA; it is appropriate to offer mediation as a tool if the person with a disability and their supporter are at odds – but the decision does lie with the person with a disability. And, agencies should be making the person with a disability aware of organizations who can help with advocacy (i.e., Disability Rights DC, Quality Trust, AJE)
- Even if supporters are dissatisfied with the outcome of mediation or whatever discussion happens when a person is dissatisfied, the person is still in charge and the agreement can still be revoked
- A person with a disability cannot be “forced” to go through mediation when they say they want to change their decision maker, but this could be encouraged and made available.
- Law says you have to have one agreement per supporter
- Training supporters is important – they should know their role – they do not make the decisions for the person
- Coordination of supporters – each person decides how they want coordination to happen
- If there are multiple facilitators, can there be one coordinator? Suggestions can be made about best practices regarding number of supporters
- Have people with disabilities meeting with doctors, lawyers, in person explaining SDM
- SDM Hotline phone number to call with questions
- Use one-page profiles!
- SDM Ambassadors at DC agencies: DBH, DC Health, DACL, ODR, OHR, DDS, Ofc Aging
- Create a “Best Practices” resource that could provide advice to agencies and community such as, 1) always talk directly to the person with a disability, not the supporter, 2) Use relationship mapping to determine a supporter or team of supporters
- There can be both formal and information supported decision making relationships

## Round 2 – Questions:

**4) What are ways we could deal with family concerns: i.e., fear for adult child, lack of supporters, fear of letting go, understanding the “logistics” of SDM**

**5) How do we support people who may be choosing something that may not be healthy for them?**

- Enlist other people who are trusted friends.
- Find a peer group for them to share pros and cons

## 6) Create a list of characteristics to consider in choosing a good supporter

- Committed, Honest, Dependable, Understanding, Caring, Patient, Empathetic, Sensitive, Curious
- Trusting – the person must trust their supporter, do you trust this person?
- Someone with emotional intelligence
- Someone who understands the DC community – resources, materials, laws, local issues
- Creative thinking/problem solver
- Someone who has integrity, is trustworthy, open to researching options for the person with a disability
- Find a contemporary, age-wise or otherwise
- Someone you already know and you know they respect you
- Someone who values your opinion on your life
- Someone with good judgment, and someone who respects the person with a disability's autonomy
- Someone who is ready to be a supporter, not the decision maker
- Age-appropriate when important to the person
- Someone who can plan for the future
- Good listener and good communicator and someone who understands how the person with a disability communicates (i.e., consider non-verbal communication, extended time to communicate, etc.)
- Family member
- Someone who understands the person with a disability's family dynamics
- Not afraid of taking risks, or stepping back to let someone make and learn from their own mistakes, someone open-minded
- Someone who knows specifics about things that are important to the person (e.g., traveling to Paris)
- Tech savvy
- Knowledgeable about assistive technology, banking, financial, housing, etc.
- Knowledgeable about field of disability
- Knowledgeable about the laws, and the rights of the person with the disability
- Effective communicator
- Someone who respects the person with a disability and understands they are a supporter, NOT the person who decides; someone who has confidence in the person with a disability and communicates that to everyone in the process
- Diplomatic and patient with the person with a disability
- Someone who is available to be present when needed
- SDM should allow the person with a disability to have positive experience and support their self-esteem – it is important for the person with a disability to not become “invisible”
- Someone who makes the person with a disability feel good; believes in, pays attention to and values the person with a disability; someone who knows the values and preferences of the person with a disability,

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	Agenda
12:30-12:55pm	Lunch & Welcome (Molly & Daisy) Review of Session #1 results
12:55-1:00pm	Rounds of discussion - instruction (Molly) Your table will be given 2-3 "questions" per round from our report from the first session, and the group would supply answers, ideas, suggestions, etc. (captured on flip chart or on notepaper) and after the group discussion - each table will report out your group's findings to the larger audience (for comment, clarification, possibly even correcting if the law was misunderstood).  In this way, we'd be building out the key elements and outlines for future trainings, and by using "adult learning" concepts, all the participants would be adding to their collective knowledge of SDM by the discussions.
1:00-1:25pm	1st Round of discussion Questions: 1) How often should an SDM agreement need to be signed, reviewed, or reassessed? How should that work? 2) How would we incorporate the use of a "team" of people as supporters (ie., a group of siblings) 3) How do we make sure all agencies and public service organizations understand SDM? How do we ensure community understands SDM? i.e., banks, medical community, companies
1:25-1:50pm	Videos: we will show a selection of SDM videos from other states: 1. <a href="#">Making Healthcare Choices: Perspectives of People with Disabilities</a> (on SDM and healthcare choices) 2. <a href="#">Supported Decision Making - Gabby's story</a> 3. <a href="#">Delaware Supported Decision-Making: Your Support, My Decisions</a> (features families, people with a range of disabilities) 4. <a href="#">Supported Decision-Making: What Supported Decision-Making is and Why It Matters</a> 5. <a href="#">Ryan on Inclusion and Decision Making</a>

1:50-2:10pm	2nd Round of discussion Questions: 4) What are ways we could deal with family concerns: ie., fear for adult child, lack of supporters, fear of letting go, understanding the “logistics” of SDM 5) How do we support people who may be choosing something that may not be healthy for them? 6) Create a list of characteristics to consider in choosing a good supporter
2:10-2:30pm	Harvest/Next Steps

Facilitator Name: \_\_\_\_\_

<p>1<sup>st</sup> Round of Discussion 1:00-1:25pm</p>	<p>1st Round of discussion Questions: 1) How often should an SDM agreement need to be signed, reviewed, or reassessed? How should that work? 2) How would we incorporate the use of a “team” of people as supporters (ie., a group of siblings) 3) How do we make sure all agencies and public service organizations understand SDM? How do we ensure community understands SDM? i.e., banks, medical community, companies</p>
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<p>2<sup>nd</sup> Round of Discussion 1:50-2:10pm</p>	<p>2nd Round of discussion Questions: 4) What are ways we could deal with family concerns: ie., fear for adult child, lack of supporters, fear of letting go, understanding the “logistics” of SDM 5) How do we support people who may be choosing something that may not be healthy for them? 6) Create a list of characteristics to consider in choosing a good supporter</p>
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